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FTORMIS

Both of these people need a life-saving drug but only one is getting it. It's time for OHIP to step up to the plate >> **BLIZZARD, PAGE 6**

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COVER STORY: HIT OR MISS

RUSSIAN ROULETTE
OF DRUG PROGRAMS

Convoluted approval process leaves patients fighting for their lives

CHRISTINA
BLIZZARD
Queen's Park

The random nature of this province's drug approval process picks winners and losers from patients looking for costly, life-saving drugs.

Patients with certain diseases are able to get funding for certain drugs, while others who are prescribed the same drug by their physicians for a different disease are turned down.

Michael Eysenga, 49, was diagnosed with atypical Hemolytic Uremic Syndrome (aHUS), a rare, devastating genetic blood disease.

It's triggered by a number of factors and causes the body's antibodies to fight one another.

In his case, it caused kidney failure and he now undergoes eight hours of dialysis five times a week.

In 2006, his wife, Margriet donated one of her kidneys to him.

Sadly, though, the medication that was supposed to stop his body rejecting the new kidney actually triggered an attack of the disease — destroying the new kidney within two weeks. Eysenga's only hope is a new drug, Solaris.

While it was approved 22 months ago by Health Canada, so far this province's convoluted drug financing process hasn't approved it for OHIP funding.

It costs about \$500,000 per patient each year.

"The government doesn't have a very good handle on how effective the medication is," Eysenga told me in a phone interview from his



Michael Eysenga, with wife Margriet, needs Solaris to stay alive, but OHIP won't cover it. Joshua DeBortoli, right, is receiving it — paid for on compassionate grounds by the drug manufacturer.



Brampton home Tuesday. While Solaris is approved for treatment of another disease, aHUS patients can't get it paid for by OHIP.

"We don't have \$500,000 sitting around," said Margriet, who works part-time as a cleaner and volunteers for the aHUS association, trying to get funding for the drug.

The first sign Joshua DeBortoli, 13, had the disease was when he turned yellow.

Mom Sonia remembers rushing him to the Hospital for Sick Children in Toronto.

"He was intubated. He had internal bleeding. He had kidney failure for 2½ weeks," she said.

He's now on Solaris — paid for on compassionate grounds by the drug manufacturer.

He has full function in his kidneys.

He's back at school, healthy, playing — and has an excellent prognosis.

"We want the government to fund the drug, but when we've been in discussion with them, I'm not sure they

understand that you can't put someone on it tentatively and then take them off of it," she said. "It doesn't work that way because it's a chronic disease."

Joshua has been on it for two years now. There are fewer than 100 aHUS patients across Canada.

"We don't have \$500,000 sitting around"

Margriet Eysenga on the cost of the drug needed to keep her husband alive

nothing more than friends and family in your constituency office who come in and are begging you to help their dying loved ones," he says. "I hate to call it picking winners and losers, but it is."

John Haslam, general manager of Alexion — the company that manufactures Solaris — says the drug is paid for in Quebec and in 40 countries around the world, including Britain and France, which have rigorous evaluation methods.

He called it "life transformative."

It would cost \$8 million to \$10 million to fund it in this province.

"If we talk about the

Canada Health Act, it really should be there for everyone," Haslam said. "Patients with rare diseases shouldn't be left behind."

In an e-mailed statement, Health Minister Eric Hoskins said the government "took the politics" out of drug funding, making sure approvals were based on the "best available evidence."

Hoskins said all drugs are thoroughly reviewed and evaluated by an expert committee.

"The committee is composed of patient representatives, physicians, pharmacists and an economist," he said.

The government is still reviewing additional information from Alexion and has a "compassionate review program," which looks at emergency situations.

Look, we all understand health dollars are stretched to the limit.

But if it's your life and your health at stake, surely every request deserves a compassionate response.

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FIRED UP



GORD MILLER/TORONTO SUN

Gord Miller talks to the media at Queen's Park yesterday after releasing his report on energy efficiency.

Commish:
Hike peak
power price

ANTONELLA ARTUSO
Queen's Park Bureau Chief

Ontarians should pay four or five times more for "on-peak" than off-peak electricity to promote conservation, environmental commissioner Gord Miller says.

The Ontario Energy Board (OEB), which sets the spread between peak, mid-peak and off-peak power rates, only has a mandate to add the cost of conservation programs onto peak power, Miller said.

"For reasons of influencing market demand, you have to really put up the price on peak," he said Tuesday. "Until they're told by the government to see it that way, it won't happen."

Time-of-use (TOU) pricing, made possible by smart meters, allows electricity providers to charge different rates depending when a customer uses hydro.

Miller said the current price for electricity used during peak winter hours — 7-11 a.m., and 5-7 p.m. on weekdays — is not quite double the cost of overnight power when demand on the system drops sharply.

Ensuring standby electricity generation to cover small peak periods of use is an expensive undertaking for the system.

Progressive Conservative

MPP John Yakabuski said that no matter how TOU rates are charged, he wouldn't support any move that would increase the overall hydro bills of Ontarians.

"They're paying too much now," Yakabuski said.

NDP MPP Peter Tabuns said the money already spent on smart meters — an estimated \$2 billion — would have been better put to loans and other financial incentives to help people lower their electricity use by making improvements, such as more energy-efficient windows.

Studies by two Ontario energy agencies concluded TOU pricing is reducing or shifting consumption from peak periods by 2%-5%, said Jennifer Beaudry, a spokeswoman for Energy Minister Bob Chiarelli.

Miller's Annual Energy Conservation Progress Report, released Tuesday in Toronto, also touched on the controversial and timely issue of carbon pricing.

The Ontario government has not ruled out participating in a cap-and-trade system or some other means of taxing carbon emissions.

Miller said Ontarians would likely reject a carbon tax if their provincial government turned it into a mere tax grab.

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